

The Scope and Impact of Perinatal Loss: Current Status and Future Directions

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The loss of an expected child can be devastating and traumatizing for parents, placing them at risk for postloss mental health complications, such as complicated or traumatic grief. The authors review the psychological and social impacts of perinatal loss and describe the standard care provided in the hospital. The authors review studies that examine the efficacy of standard care and highlight the need for empirical evidence confirming the efficacy of these current interventions. The authors provide recommendations for health care professionals in contact with the perinatally bereaved and suggest areas for future research.

Keywords: depression, maternal anxiety, perinatal loss, traumatic grief

In 1999, approximately 1% of births in the United States resulted in perinatal loss, defined as fetal death beyond 20-weeks gestation through infant death 1-month postpartum (Hoyert, Smith, & Arias, 2001). The unanticipated and shocking loss of an expected child can be devastating and traumatizing for parents. As a result, this kind of loss places the bereaved at risk for postloss

mental health complications (Bonanno et al., 2002). However, as is the case with most traumatic losses, after an initial period of shock, distress, and mourning, the majority of individuals or couples who suffer a perinatal loss regain a sense of purpose and adjust well, often as a result of having another child (Conway & Russell, 2000; Swanson, 1999). Although most couples recover through their own resourcefulness and resilience, studies suggest that 15% to 25% of women who experience perinatal loss have enduring adjustment problems and many seek professional help to guide them through this difficult time (e.g., Hughes, Turton, Hopper, & Evans, 2002; Klier, Geller, & Neugebauer, 2000; Swanson, 1999). At present, the various factors (individual, familial, economic, medical, cultural, and religious) that affect long-term psychological reactions to perinatal loss are not well known.

Perinatal loss is likely to become a more pressing clinical problem in the future because of the increasing use of fertility services such as in vitro fertilization and more expeditious diagnosis of impending intrauterine fetal demise (IUID; e.g., Cote-Arsenault & Mahlangu, 1999). In this article, we review studies that describe the psychological and social impact of perinatal loss. We also describe the standard care provided to bereaved individuals in the hospital and review studies that examine the efficacy of standard care. Last, we offer an alternative framework for early intervention and provide recommendations for future research.

The Nature of Perinatal Loss

The Unique Nature of Perinatal Loss

Perinatal bereavement is uniquely devastating and shocking to parents who may expect to experience profound joy as a result of giving birth. There is typically nothing in a person's background that can prepare him or her for perinatal loss. Instead of giving life as expected, parents must grapple with death and with mourning a

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child who, in most instances, was imbued with promise and expectation. In the spectrum of potentially traumatic losses, perinatal loss is unique for many reasons. For example, parents never know or have shared experience with the lost person-to-be. When an adult dies, a piece of the past is lost; however, when an infant dies, a piece of the future is lost, or significantly changed forever. Thus, the loss of a child perinatally entails the loss of anticipated joy, parenthood, relationship enhancement, and standing in the culture. In addition, the love, energy, time, and commitment expended to bring the child into the world go unrewarded. Contrary to other child losses, society often views perinatal loss as insignificant, leaving parents feeling extremely alone and invalidated in their grief (Vance et al., 1995). A parent may feel the world goes on as though their child and their role as a parent were not just lost but never existed.

Perinatal loss is sometimes considered a "silent loss" because others may not feel comfortable talking about the loss with the family. For most people, there is no prior knowledge to use as a reference point and no experiential history, which makes it difficult for significant others to empathize. This dynamic further distinguishes perinatal loss from other types of bereavement. Although family members and friends may have been supportive during the pregnancy and excited about the upcoming birth, these same individuals may not know how to handle the death or offer condolences; thus, they withdraw support from the bereaved parents (De Montigny, Beaudet, & Dumas, 1999). The loss of a child and all the child has to offer, compounded with the societal attitude discounting the loss and the potential withdrawal of social support, may leave the bereaved parents feeling distraught and alone at a time that was supposed to be full of happiness.

The Initial Phenomenology of Perinatal Loss

A woman may realize that she has an impending loss or has suffered a perinatal loss in several different ways. Some women may be visiting the doctor for a routine check-up when no fetal movement or heartbeat is detected. Other women may come to the hospital in labor and then deliver a child who is stillborn or who dies shortly after birth. With neonatal loss, a subcategory of perinatal loss, the baby may be liveborn but dies within 1 month of delivery, as a result of prematurity, physiological complications, or genetic anomalies. Regardless of the form of perinatal loss, most couples respond to the impending or confirmed loss with shock, horror, and confusion (Vance et al., 1995). In addition, if a woman has undergone a procedure (dilation and curettage or dilation and evacuation) or has gone through labor, with or without a cesarean-section delivery, she may be concomitantly dealing with the physical pain and discomfort resulting from the procedure or surgery. When the loss occurs, there is a precipitous transition from pregnancy to nonpregnancy, with little time to prepare for and integrate the sudden change. Parents are often asked to make decisions about burial and/or the disposition of remains when they are physically and emotionally in pain (Leon, 2001). They have to face the task of explaining what happened to family and friends, when they themselves may not fully understand what happened, because often there is no identifiable cause (Nikcevic, Kuczmierczyk, Tunkel, & Nicolaides, 2000).

Familial Consequences of Perinatal Loss

A perinatal loss can cause strain on a marriage as each member of the dyad is coming to terms with the loss in his or her own way (de Montigny, Beaudet, & Dumas, 1999; Samuelsson, Radestad, & Segesten, 2001). The couple's communication may deteriorate during this time, when feelings of loss are overwhelming and difficult to express. Or, as each partner may try to protect the other, they stop talking and sharing their more painful thoughts and feelings. A couple can feel quite isolated, as though no one knows what they are going through and may retreat from their usual social circles because it is too painful to see other families with children (de Montigny et al., 1999). A perinatal loss can also cause a woman to feel like her body has betrayed her, as though there is something wrong with her womanhood, and there may be self-blame and guilt (Cote-Arsenault & Mahlangu, 1999).

Fathers' reactions to a perinatal loss can be different from their partners' because they have not been carrying the child, although an attachment to the child is still present and the meaning of the child may be no less significant (Conway & Russell, 2000; Samuelsson et al., 2001). Many fathers report feeling helpless and angry at the pain the mother of their child is experiencing and may focus on being present to her needs instead of attending to their own grief. The grief of the father is sometimes overlooked because family and friends may immediately focus on the pain the mother is feeling (Conway & Russell, 2000; Samuelsson et al., 2001). Although fathers tend to report less symptoms of psychopathology, the experience can be troubling nonetheless, which suggests that caregivers should acknowledge, and be attentive to, the grief of partners and/or fathers as well as that of mothers.

A perinatal loss can affect how a family functions (de Montigny et al., 1999; Grout & Romanoff, 2000). In this context, mothers' distress can affect parenting style and the attachment behavior of the next-born infant (Allen, Lewinsohn, & Seeley, 1998; Hughes, Turton, Hopper, McGauley, & Fonagy, 2001). Siblings of an infant who dies are dually affected by the loss. These children or adolescents may feel sadness at the loss of a brother or sister but are also indirectly affected by the grief and sadness they witness around them. Parents may have problems supporting their children during this difficult time, particularly if the parents experience significant mental health symptoms and functional impairment (de Montigny et al., 1999; Grout & Romanoff, 2000; Wilson, 2001).

The Effects of Perinatal Loss on Attachment

Perinatal loss marks the end of a very unique and important attachment. Arguably, the loss is particularly devastating and traumatic for those parents who were invested in having a child or who developed a very strong bond in utero. In a perinatal loss, the strength of the attachment bond is not dictated by the gestational age of the child because the attachment to an unborn child begins at different points for each individual (Cote-Arsenault & Mahlangu, 1999). For some women, the salience and importance of motherhood begins in youth, whereas for others, the emotional significance may not be manifest until the abdomen is "showing." Peppers and Knapp (1980) studied the mother-child bond and concluded that this attachment often begins long before the birth of the child. They proposed nine events or milestones that likely contribute to the attachment that is formed, including (a) planning

the pregnancy, (b) confirming the pregnancy, (c) accepting the pregnancy, (d) feeling fetal movement, (e) accepting the fetus as an individual, (f) giving birth, (g) seeing the baby, (h) touching the baby, and (i) giving care to the baby (Peppers & Knapp, 1980). Prebirth events can intensify the attachment the mother and/or parents feel toward their unborn child. The investment and meaning of the pregnancy and potential parenthood are highly variable, but are likely affected by the amount of time and energy spent trying to conceive, the fertility history of the couple, the amount of outside help sought to conceive (e.g., in vitro fertilization), the amount of time and planning put into preparing for the birth, the age of the mother, previous pregnancy losses, the number of living children, the current state of the relationship between the parents of the child, and any outside influences and expectations about having a child (e.g., family pressures). To date, these factors have not been studied comprehensively.

Mental Health Outcomes Associated With Perinatal Loss

Extant Research

Researchers have primarily evaluated the mental health consequences of perinatal loss in expectant mothers who previously suffered such a loss. Pregnancy after a perinatal loss is an important milestone, which may trigger reexperiencing of the prior loss (Cote-Arsenault & Bidlack, 2001; Turton, Hughes, Evans, & Fainman, 2001). Nevertheless, because research has focused chiefly on expectant mothers, very little is known about the functioning of women who are unable or choose not to get pregnant after experiencing a perinatal loss.

To date, clinicians and researchers have assumed that perinatal loss creates risk for posttraumatic stress disorder (PTSD) and depression. Turton et al. (2001) estimated the lifetime risk for PTSD from perinatal loss to be 29% and the risk for PTSD manifested in a subsequent pregnancy is 20%. Hughes et al. (2002) reported that approximately 20% of women who experience a perinatal loss have prolonged depression and another 20% develop PTSD. Vance and colleagues (1995) compared 220 perinatally bereaved families with 226 families who experienced successful birth and found that the bereaved families reported significantly more symptoms of depression and anxiety 2 and 8 months after the loss, although their symptoms decreased significantly between these two time points. Mothers' anxiety and depression was higher than fathers at both follow-up intervals (Vance et al., 1995).

Traumatic Grief

In our view, the terms *complicated bereavement* or *traumatic grief* represent a syndrome that best captures the enduring mental health impact of perinatal loss (e.g., Prigerson et al., 1999). As proposed, traumatic grief constitutes a syndrome distinct from normal grief, PTSD, and depression, with the stressor explicitly identified as the traumatic loss of an important attachment figure (Neria & Litz, 2004). The specific components of traumatic grief that differentiate it from depression include the meaning and significance of the attachment that was lost. Studies have shown that symptoms of traumatic grief differ from those of depression in time and course (Pasternak et al., 1991) and electroencephalogram sleep architecture (McDermott, Prigerson, & Reynolds, 1997). In

addition, symptoms of traumatic grief are associated with risk for other mental and physical health problems, including suicidality, heart attack, and illness, which may lead to death (Prigerson et al., 1999). Most studies of perinatal loss fail to include traumatic grief as a potential outcome, in part, because it is assumed that PTSD is the sole pressing mental health problem associated with severe loss. In addition, traumatic grief is not currently a formal diagnosis associated with a set of prescriptive interventions (Gray, Prigerson, & Litz, 2004). Studies comparing PTSD, depression, and traumatic grief are needed to determine the descriptive framework with the most construct validity.

Clinical Interventions for the Perinatally Bereaved

Perinatal loss affects women from all demographic groups, regardless of age, socioeconomic status, or the quality of medical care. In the acute phase, perinatal loss is typically addressed in hospital, obstetrics and gynecology outpatient clinics, primary care clinics, and family planning centers. Women with distress resulting from perinatal loss may also present in any agency or care setting that deals with female patients or families. Therefore, our position is that a basic understanding of perinatal loss, and the current standard of care for women who experience perinatal loss, would be useful for many medical and mental health professionals.

Standard of Care: Past and Present

The care and management of perinatal loss have varied considerably over time. Historically, a perinatal death was not considered a significant loss and did not become part of a family's birth history (Leon, 2001). The dead infant was immediately taken away from the parents after delivery and tranquilizers were provided to the mother to dampen any distress (Lasker & Toedter, 1994; Leon, 2001). The loss was not often discussed and the couple was given little support or opportunity to grieve (Lasker & Toedter, 1994; Leon, 2001). Today, standard practice in most hospitals and birthing centers is quite different. In an effort to promote recovery from the loss while patients are in the hospital, multidisciplinary teams provide support, validation, and assistance in planning for the adjustment period posthospitalization. It is standard to facilitate grieving by encouraging the parents to consider having direct contact with their dead or dying infant, including seeing and/or holding the baby. Parents are often provided with mementos to take home, including photographs of their dead child, a lock of hair, a footprint, and possibly a blanket. Many hospitals provide the services of a chaplain and/or a social worker to help the couple with bereavement and funeral planning, which in some states is mandated by law (Hughes et al., 2002; Lasker & Toedter, 1994). Some hospitals and/or community groups offer support groups so that couples have a place to grieve with others thereby reducing stigma and isolation (see Appendix; Cuisinier, Kuijpers, Hoogduin, de Graauw, & Janssen, 1993; Hughes et al., 2002; Lasker & Toedter, 1994). A social worker or bereavement counselor often follows up with the couple some weeks later to assess how they are coping, offer additional support, and offer a mental health referral when necessary (Leon, 2001). Some programs send a card on the anniversary of the child's death to commemorate the loss and to acknowledge that this may be a difficult time for some parents.

It is ideal for a social worker, chaplain, or other counselor to try to meet the patient or couple predelivery but that is not always possible due to the medical situation (active labor) or to staffing constraints. The goal of the early meetings is to give the patient or couple an opportunity to talk about the fear, shock, and surprise that often accompanies them, because many have only recently learned that the fetus is not viable. The meeting also serves as an opportunity to do some anticipatory work about the labor and the aftermath, including whether they might want to see, hold, and/or name the baby. After delivery, the meetings focus on the patient or couple talking about the labor and delivery and the decision and experience of seeing, holding, and naming the baby. Subsequent in-hospital discussions focus on bereavement work and practical realities such as funeral planning and how to talk to family, friends, and younger siblings. On the basis of an assessment of the patient's or couple's coping styles, strengths, and previous psychiatric and substance abuse histories, psychoeducation is provided, recommendations about what the patient or couple might anticipate in the weeks/months after the loss are reviewed, and information about how to access formal and informal supports is imparted. Follow-up phone calls vary in length, depending on the needs of the patient. Again, the focus of this phone intervention is bereavement counseling, psychoeducation, and provision of referral information, should the person need to be referred for more ongoing mental health.

Empirical Evidence

On average, it appears from uncontrolled studies that patients are satisfied and appreciative of the care they receive in the hospital (Cuisinier et al., 1993; Lasker & Toedter, 1994). On the other hand, some studies have shown that standard practices may increase distress following a perinatal loss. One recent large-scale, retrospective cohort study compared pregnant women who had previously experienced a stillbirth with a control group of women experiencing their first pregnancy (Hughes et al., 2002). These researchers also compared women within the stillbirth group who saw and held their dead baby with those who did not. Hughes and colleagues (2002) found that women who saw and held their dead babies reported significantly higher depression and PTSD symptom severity in the third trimester of their subsequent pregnancy than both of the comparison groups and significantly higher PTSD scores 1 year after their subsequent birth. These results suggest that standard procedures may be counterproductive and possibly put women at higher risk for mental health complications. Perhaps some individuals may be more distressed and haunted by the loss if they are asked to process the loss prematurely or in a manner that is inconsistent with their personal style and current needs (cf. Bonanno et al., 2002).

However, it is important to underscore that the internal and external validity problems of Hughes et al.'s (2002) study weaken the conclusions that can be drawn. The study compared self-selected groups of women and relied on retrospective accounts of loss experiences in women who were about to deliver their next child. The women may have inflated reports of distress and anxiety concerning their previous loss because of pregnancy-related stress. Furthermore, the study is not applicable to a significant group of women who chose not to have a subsequent child or who were not able to become pregnant following their loss. Hughes et al. also

failed to account for a number of other variables that could explain their findings, such as the strength of maternal attachment, the number and quality of caregivers present, coping style, type of loss, age of mother, previous mental health services such as grief counseling and/or medications, and social support, all of which may have influenced the women's choice to see and hold their babies as well as influenced the differential outcome between women who chose to do so and those who did not. Randomized controlled trials of the standard of care are needed to determine definitively the efficacy of current practices.

How might standard practices be helpful and welcomed for some, yet inappropriate and iatrogenic for others? By returning to the nine events Peppers and Knapp (1980) purported as contributing to the formation of the mother-infant bond, some light can be shed on this question. Going through the process of birth, seeing the baby, and touching the baby after the child has died may strengthen the mother's (or parents') attachment to the child and help to create a lasting memory of the child. On the other hand, these experiences may also force the parent(s) to confront intense feelings of sadness, grief, and shock in a possibly premature fashion, which for some, may be counter-therapeutic. Hughes and colleagues (Hughes & Riches, 2003) also suggested that examining current practices in their cultural and social contexts may help to reconcile the varying impact of standard practices. For example, whereas in some cultures seeing a dead infant may be therapeutic and rituals that are part of the standard care may feel important and healing, other cultures may have negative beliefs, superstitions, and meanings attributed to viewing and touching the dead. Although the ritual seeing and holding of the dead fetus are designed to give recognition, meaning, and significance to the lost child, it may be that standard practices need to be reconsidered or perhaps simply better tailored to fit differing families' needs.

In terms of evaluating the standard interventions provided in hospitals for perinatally bereaved parents, including exposure to the deceased baby and immediate grief counseling, it is important to examine critically the conceptual underpinnings of the modal approach to care. Historically, "grief work", or early, intense, and visible grieving, was seen as the exclusive vehicle to recover from any loss (see Bonanno et al., 2002; Hughes & Riches, 2003). Grief counseling is predicated on the assumption that anyone who loses a loved one tragically or in a complicated fashion needs help to promote the prototypic grief process. It is used as a vehicle to uncover or unearth various manifestations of grief, such as protest, anguish, sadness, and life review, which, if not manifest, may place the person at risk for postgrief mental health complications. This is the overarching model used to guide early intervention for perinatal bereavement in the hospital to facilitate grieving in the hours or days after the loss. However, a wealth of social science research has revealed that there is tremendous variation in the timing, intensity, valence, and visibility of grief reactions. Essentially, there is no normative or prescriptive mode of grieving; intense emotional expressions and self-disclosure can lead to worse outcomes and apparent stoic reactions can lead to adaptive recovery (e.g., Bonanno et al., 2002). As a result, standardized applications of grief counseling, even for tragic and potentially traumatizing losses such as perinatal bereavement, are at risk for being inadvertently disruptive to an individual or couple's manner of adapting. On the other hand, because some losses for certain individuals can lead to devastating and chronic mental health

problems, some kind of early screening or intervention is indicated.

Early Intervention for Trauma

At present, the entire field of early intervention for trauma and traumatic loss is undergoing a paradigm shift (Litz, Gray, Bryant, & Adler, 2002). Standard practices of crisis intervention and grief counseling are being challenged on empirical and conceptual grounds. Empirically, there is insufficient scientific evidence to support the use of crisis interventions or grief counseling. Because the large majority of people adjust to the most horrific life experiences and losses effectively on their own or in their natural social context, standard applications of early intervention to all victims are bound to be seen as effective because they capitalize on recovery that would have happened anyway (e.g., Litz & Gray, 2004). Thus, in the best case, crisis and grief counseling approaches may be unnecessary and a misapplication of resources. In the worst case, providing early intervention for perinatally bereaved parents could be experienced as intrusive and promote a process that may be iatrogenic for some. On the other hand, there are those who suffer a perinatal loss who will not do well on their own over time; they are at risk for suffering a chronic complicated grief reaction and possibly other mental health problems. Although it is safe to say that early intervention for traumatic loss is indicated for at-risk mothers and fathers, the state of the science in this field is uncertain with respect to who should be targeted, when it is best to intervene, and what techniques to use (Gray et al., 2004). For example, the most beneficial timing for grief counseling among traumatically bereaved individuals is unclear, and intervention timing is highly variable in existing studies (Schut, Stroebe, Van Den Bout, & Terheggen, 2001). Nevertheless, we argue that it is important for multidisciplinary health care professionals not to be immobilized by the lack of evidence in the field with respect to how mothers and family members should be treated when perinatal loss occurs. In this context, it is important to appreciate the distinction between palliative and supportive interventions and formal efforts at secondary prevention of psychopathology from loss (Litz et al., 2002).

Implications and Applications

Recommendations for Care

In our view, it is important that all health care professionals who interact with mothers or parents who have suffered a perinatal loss do so in a supportive, empathic, patient, and respectful manner. Care providers should be accepting and validating of the individual's experience, provide accurate information, inquire about each individual's needs, empower each person to decide the kind of help he or she wants, and assist with problem solving. It appears that validation of the importance of the loss is particularly meaningful for parents bereaved by perinatal loss (Cote-Arsenault & Mahlangu, 1999; Cuisinier et al., 1993; Lasker & Toedter, 1994; Samuelsson et al., 2001). These various supportive and humane practices in the immediate postloss context come under the heading of *psychological first aid* (Litz et al., 2002; Raphael, 1977). Psychological first aid does not serve a secondary prevention function (i.e., it does not function to reduce risk for postloss mental

health problems). It is designed to avoid neutral, disrespectful, insensitive, or invalidating treatment that would indeed be harmful. The goal of psychological first aid is not to maximize grieving or to provide advice, interpretation, or other directive interventions. The measurable outcomes that should be evident when psychological first aid is used are as follows: perceived social support, reduced stigma, increased help-seeking, greater self-care, and understanding and acceptance of the loss experience.

In contrast to psychological first aid, formal evidenced-based secondary prevention interventions for loss require multiple outpatient sessions where the individual is an active participant in emotionally processing the loss, reframing the loss, and implementing a plan of action as occupational, interpersonal, and self-care demands emerge over time (Litz & Gray, 2004). In the immediate aftermath of perinatal loss (i.e., while mothers are still in the hospital), individuals may not be prepared to attend sufficiently to formalized evidenced-based mental health interventions. Instead, we suggest that information should be provided to mothers and parents about the signs and symptoms that might require formal mental health intervention in the coming days, weeks, and months after their discharge. Hospital staff should also inquire about supports and resources that are available to the patient so as to mobilize those resources to help support the bereaved parents. Parents can be helped to think about coping skills and self-care techniques that have helped them in the past and encouraged to use these strategies. If possible, parents should be asked if they would accept an outreach phone call 1 to 2 weeks after discharge to reassess their well-being and to address the need for more formal mental health intervention.

At present, there is no prescriptive or gold-standard secondary prevention intervention for perinatal loss-related problems. Indeed, there is no published working model for outpatient secondary prevention or therapy for perinatal loss. We argue that a specialized form of treatment will be required because of the unique nature and impact of perinatal loss. We recommend that psychologists should keep the following in mind if they have patients who present with perinatal loss or have patients in ongoing psychotherapy who suffer this kind of loss. Because women and couples may feel crazy or defective if they can't "snap out of it" after a few weeks or months, they should be provided psycho-education about the bereavement process, allowing for great variability in response to loss and rate of recovery. In some instances, extended family members may benefit from education about perinatal loss and about ways they can be helpful to the aggrieved parents. Health care providers should allow the woman or couple (or the whole family) an opportunity to talk about the loss, their response to it, and the perceived lasting personal implication of the loss. Here too, it is important to allow great latitude in outward expressions of loss-related feelings and not to press people to emotionally process the loss beyond their capacity to do so normally. If the parents have named their baby, providers should not be afraid to use the baby's name as it can be comforting to parents when others recognize their lost child as "real." If the woman or couple is immobilized or consumed and ruminative, the therapist should provide assistance with enhancing self-care routines and promoting reinforcing and pleasurable activities. If patients are severely avoidant, they should be encouraged to gradually engage in avoided activities (e.g., attending baby showers, attending holiday functions).

Therapists should be aware of the meaning and significance of the hospital-based rituals and interventions, such as seeing or holding the dead fetus and taking photographs of the child. Some women may still be struggling with their choices in the hospital or the emotional aftermath of the rituals. This topic should be broached and processed accordingly. Because anniversaries may trigger anguish for some women or parents, therapists should track the anniversary of the loss when appropriate and normalize the fact that this will be a particularly difficult time (i.e., symptoms may re-peak during this interval). Women or couples are most likely triggered to recall the pain of perinatal loss when they contemplate or negotiate a next pregnancy (Hughes et al., 2002). As a result, this time period may require special consideration. For example, if the woman or couple has excessive fear that the loss will happen again, the therapist may help process these fears, challenge any maladaptive thoughts related to these fears (e.g., "I will never be able to have a normal pregnancy and/or child"), and consider anxiety management techniques to assist in coping during difficult times.

Directions for Future Research

To date, there have been no randomized controlled trials of early secondary prevention interventions for traumatic grief or complicated bereavement (Gray et al., 2004; Neria & Litz, 2004). There is preliminary evidence from uncontrolled trials that cognitive-behavioral treatment (CBT) reduces the risk for chronic postloss psychopathology. For example, Shear et al. (2001) published pilot data for an intervention designed specifically to target symptoms of complicated grief. The intervention was applied only to individuals experiencing significant symptoms of complicated grief and consisted of 16 weekly sessions of individual therapy. The intervention included imaginal and in vivo exposure to cues and situations that the bereaved individual had been avoiding. Interpersonal therapy methods were also used to facilitate social reengagement and processing the meaning of the loss. Patients shared the history of the relationship, provided an account of the circumstances surrounding the death, and described present relationships. A psychoeducational component was included to familiarize patients with symptoms of complicated grief. Individually tailored hierarchies of avoided situations were obtained and imaginal and in vivo exposure exercises were conducted. The imaginal exercises were tape recorded and patients were instructed to listen to these daily between sessions as homework assignments. Both the completer group (13 of 21 who began therapy) and the intent-to-treat participants exhibited significant reductions in symptoms of complicated grief, depression, and anxiety.

At present, we do not have sufficient knowledge about the risk and resilience factors that shape the trajectory of adaptation to perinatal loss. We also do not know whether standard care is necessary or sufficient, or, in the worst case, iatrogenic. Thus, future research requires a two-pronged approach, namely, (a) well-designed cross-sectional and longitudinal epidemiological studies that will generate knowledge of the impact, course, and predictors of perinatal bereavement and the mental health outcomes associated with this unique loss, and (b) randomized controlled trials of standard early interventions compared with novel treatments that will determine the best approaches to care.

To augment efficacy studies on early intervention for perinatal loss, it would be helpful to have data on current practices being performed at hospitals and birthing centers across the country and around the world. As there is not an established gold-standard, universal method to follow in caring for women and families after a perinatal loss, there is no definitive information about how health care facilities care for these patients. For example, at any given hospital, do caregivers leave the decision about whether to see the dead baby entirely up to the family or do they make a formal recommendation, which may or may not influence the family's decision? A large-scale, national survey study of a representative sample of hospitals and care centers across the United States would inform researchers of the range of practices and/or interventions currently being used. This kind of research will also reveal whether there are hospitals or regions where there may be a need for dissemination of current knowledge on caring for patients who experience perinatal loss.

In terms of future epidemiological research, there are a host of variables that are likely to affect how parents react to the loss of their child and how they adapt to this potentially traumatic bereavement over time. Because most parents adapt well, it is important to identify the mediators that cause or attenuate risk for untoward mental health response. The most important variables to examine are (a) the acute context of the loss, including the suddenness of the crisis, what is known about the cause of the loss, and the mothers' perceived responsibility for the loss (e.g., feelings of guilt); (b) the strength of the attachment to this child; (c) the meaning of the birth for the mother, the father, the nuclear family, and the extended family; (d) the process and the context of conception and the pregnancy, including the amount of time spent trying to conceive, the fertility history of the couple, the amount of time and planning put into preparing for the birth, the age of the mother, the existence of any previous pregnancy losses, the existence and number of living children, and the current state and/or strain of the relationship between the parents of the child; (e) preexisting trauma and loss history and preexisting mental health problems; (f) financial and social support resources; (g) religious beliefs; (h) various specific and general medical care and other in-hospital experiences, including the experience of formalized grief-promotion practices and feelings of support and positive care while in the hospital (e.g., feelings that the individual was well taken care of postloss); (i) individual differences in emotional processing and coping style; and (j) grief rituals that may or may not be offered and/or performed.

It is worth expanding on the impact of culture and religion as potential mediators of outcome from perinatal loss. Different cultures have very different expectations about having children, as well as different notions regarding the meaning of parenthood, the meaning of death, and the existence of an afterlife. Ideas regarding the role of the woman in the family structure also differ across cultures and can affect how a woman or couple interprets and processes perinatal loss (Hughes & Riches, 2003). The knowledge and beliefs a person has about modern medicine and biology are also strongly influenced by culture and religion, which may affect a person's thinking about why the loss occurred and how it is then processed (Swanson, 1999). Last, culture, language, and religious beliefs can affect how a mother, couple, or family experiences and comprehends the loss, the care they are provided, and the kind of assistance they may be able to use (e.g., a support group). For

example, in some cultures, losing a child may be an extremely shameful experience, and individuals operating within this culture may keep the loss a family secret, seeking support solely within the familial context. Because of the enormous diversity in America, particularly in large cities, it may be particularly prudent to maintain a multicultural perspective of perinatal loss to best serve all patients.

Future research should examine the efficacy of early psychological first aid and formal secondary prevention interventions designed to prevent chronic complicated grief in mothers and parents who experience perinatal loss. This research should follow the standard guidelines of rigorous randomized controlled trials (manualized intervention, reliability checks, formal psychometrically valid assessment, blind assessment of outcome, and intent-to-treat analysis). Because preliminary research suggests that certain graphic aspects of standard practices may lead to worse psychological outcomes (Hughes et al., 2002), it will also be important in future research to examine the efficacy of various aspects of standard care (e.g., having the parents hold their dead child). Satisfaction with care should also be carefully examined within this context. Overall, more rigorous scientific investigations of families who experience perinatal loss will inform caregivers about the best way to facilitate recovery from this unique bereavement experience.

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Appendix

National Perinatal Loss Support Resources

Alliance of Grandparents, A Support in Tragedy International (AGAST): P.O. Box 17281, Phoenix, AZ 85011; (888) 774-7437. Provides support for grandparents who have lost a grandchild and gives information on how to help their children (the parents).

American SIDS Institute: 2480 Windy Hill Road, Suite 380, Marietta, GA 30067; (800) 232-SIDS. Provides information and crisis phone counseling.

Angel Babies Forever Loved: P.O. Box 243196, Boynton Beach, FL 33424; (561) 596-7877. Supports grieving parents who have suffered a loss due to miscarriage, stillbirth, neonatal loss, or SIDS.

Bereaved Parents of the USA: P.O. Box 95, Park Forest, IL 60466. Educates families about grief and sponsors support groups. Chapters in 17 states.

CLIMB (Center for Loss in Multiple Birth): P.O. Box 91377, Anchorage, AK 99509; (907) 222-5321. By and for parents who have experienced the death of one or more babies from a multiple pregnancy.

The Compassionate Friends: P.O. Box 3696, Oak Brook, IL 60522; (877) 969-0010 or (630) 990-0010. National nondenominational self-help organization offering support and friendship to families following the death of a child. Over 500 chapters nationwide.

Hygeia: A global community for perinatal health, loss, and bereavement using new technology to share feelings and lessons.

Mommies Enduring Neonatal Death (MEND): P.O. Box 1007, Coppell, TX 75019; (888) 659-MEND. Christian support group; reaches out to those experiencing miscarriage, stillbirth, or early infant death.

National SIDS Resource Center: 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182; (703) 821-8955. A federally funded resource center that provides information to families and health care providers.

A Place to Remember: 1885 University Avenue, Suite 110, St. Paul, MN 55104; (800) 631-0973 or (651) 645-7045. Provides materials and resources to those who have had a crisis in pregnancy or who have lost a baby.

Pregnancy and Infant Loss Center: 1421 East Wayzata Boulevard, #70, Wayzata, MN 55391; (952) 473-9372. Provides support, information, and resources to parents who have lost a child through miscarriage, stillbirth, or infant death.

Pregnancy Loss Support Program: National Council of Jewish Women, New York Section, 820 Second Avenue, New York, NY 10017; (212) 687-5030, ext. 40. Coordinates telephone counseling service and support groups.

Remembering Our Babies: 2710 Knoxville Drive, League City, TX 77573; (281) 316-6330. Sponsors Pregnancy and Infant Loss Remembrance Day.

SHARE Pregnancy and Infant Loss Support: St. Joseph Health Center, 300 First Capitol Drive, St. Charles, MO 63301; (800) 821-6819 or (636) 947-6164. Nondenominational organization that offers support to parents and others touched by the death of a baby through early pregnancy loss, stillbirth, or newborn death. Over 130 chapters worldwide.

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